PAIN CARE COALITION

A National Coalition for Responsible Pain Care

American Academy of Pain Medicine • American Headache Society • American Pain Society• American Society of Anesthesiologists

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Testimony of

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Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to appear before you today. I welcome this hearing, and I applaud your leadership and that of Congressman Rogers, in bringing national attention to pain as a major public health problem in this country.

I am Joel Saper, Founder and Director of the Michigan Head Pain and Neurological Institute in Ann Arbor, Michigan, and Chair of the Pain Care Coalition. I am also a current or past president/officer or director of the American Headache Society, the American Pain Society and the American Academy of Pain Medicine, among others. I am a board-certified neurologist and pain specialist, and Clinical Associate Professor of Neurology, and I have devoted my entire professional life (35 years), through research, teaching, and clinical practice, to improving the lives of people who suffer from pain.

The Problem

Mr. Chairman, the problem of pain in this country is of enormous size:

- Pain is the most common reason people seek medical help.
- Over 100 million Americans suffer from continuous or frequent pain.
- Chronic pain is a leading cause of disability, both temporary and permanent.
- Reduced productivity due to pain costs employers somewhere between $60 and $100 Billion annually.
- The total cost of pain to the health care system and the broader economy cannot be currently calculated but is larger than any other health care condition, such as heart disease, hypertension, or diabetes. A single example--chronic back pain—is estimated to add over $25 Billion annually to national health care costs.
- Most illnesses lead to pain, and chronic pain leads to many other illnesses. From the acute pain of trauma or surgery or sickle cell disease or severe burns to the chronic pain of cancer, heart disease, AIDS, MS, arthritis, bone disease, diabetes, colitis, back and neck disorders, migraine, fibromyalgia, RSD, TMJ, and on and on and on, pain cuts indiscriminately across demographic lines, and across the populations that this Subcommittee does so much to serve—the elderly, the disabled, and the medically indigent.
- Pain can kill: it can kill the spirit, vitality, and the will to live. Pain also alters the immune system and makes its victims more vulnerable to other diseases. Moreover, loss of income, careers, quality of personal and family life, and the joy of living are trumped by the daily and persistent agony of pain and the desperation and isolation that come with

it. The lives of those afflicted and their families are placed on the brink, if not defeated altogether.

- And despite great scientific strides in the past decade, improved treatment facilities and techniques, the availability of powerful medications, and credentialed specialists, we are far from accomplishing a satisfactory impact on this enormous world-wide health problem. Too many people suffer daily, severe pain. We have no panaceas. We need more knowledge and more tools

The Federal Research Commitment

I understand that the Subcommittee's primary interest today is in assessing the adequacy of federal research on chronic pain. It is discouraging to report that, half way through the Congressionally-declared Decade of Pain Control and Research, that research commitment is woefully inadequate, and hardly proportional to the burden pain imposes on the population. An exhaustive study of NIH pain research, based on FY 2003 grant awards, concluded that NIH devotes a scant 1% of its research budget to projects with a primary focus on pain. Broadening the inquiry to include grants that have some, perhaps only marginal, relationship to pain, only adds another 1 and 1/2% of the pie. While longitudinal data is not readily available, there is little indication that NIH considers pain research to be a higher priority, in any sense of the word, today than it was ten years ago.

Nor does the data suggest a concerted effort to prioritize what little the NIH does invest in pain, or to coordinate that investment across Institutes, Centers and programs. If back pain costs the health system $26 Billion annually, is an investment in all forms of musculoskeletal pain research of less than $50 Million—one fifth of one percent-- reasonable? If cancer pain gets another $50 Million, why does cardiac pain get less than $2 Million, or headache less than $20

Million? To put the latter figure in perspective, it represents less than one dollar a year for each and every migraine sufferer in this country. And if cancer pain does get $50 Million, why is a third of that funded through channels other than the National Cancer Institute? Or, if some Institutes devote 80% or more of their pain research effort to basic research, why do others spend 90% or more on clinical research at the expense of basic research?

Immediate needs for expanded research in pain include, among many others, the following broad areas:

- Basic research to more fully understand complex mechanisms of pain perception and development in the brain;
- Better understanding of the linkages between brain mechanisms and emotions that effect the perception and severity of pain;
- Basic and clinical research into how acute pain (e.g. post operative or trauma pain) becomes chronic pain, and how to prevent it; and
- Better understanding of the long term risks of current therapies on brain function and long term pain prevention.

Mr. Chairman, I could go on but time does not permit, and we will make this data and other research priorities available to you and your staffs so that you may draw your own conclusions from it. Let me instead suggest some possible solutions.

Recommendations

The enormity of pain as a public health problem demands a comprehensive federal response promoting research, education and access to care. For this reason, the Pain Care Coalition and dozens of other professional and patient advocates strongly support HR 1020, the

National Pain Care Policy Act, introduced by Cong. Rogers. It is the only comprehensive pain bill pending in the current Congress. Indeed, it is the only comprehensive pain bill ever introduced in the Congress, and I urge you to hold further hearings in this Subcommittee to explore problems of education and access which are equal in importance to those of research which we are discussing today.

Short of a comprehensive and long term response to the major public health problem which pain represents, there are a number of short term measures in the area of research alone which the Subcommittee should consider.

First, I understand that both Congressional and NIH leadership are seeking more effective "trans Institute" coordination of research activities. Chronic pain research would be a natural candidate for such an initiative. With funding spread across three principal Institutes, and a dozen more with smaller concentrations, the benefits of enhanced coordination and cross fertilization could be significant. NIH's existing "Pain Consortium," which now exists mostly in theory, could, with modest funding and staff, become a powerful tool for assessing and setting priorities across the various offices with a stake in pain research.

Second, better information could be a powerful tool for better prioritization of research dollars. The data I described a few moments ago were gleaned from NIH records by private researchers. NIH itself should be required to explain to this Committee and other interested legislators what it does on pain each year, why it focuses where it does, and what is being accomplished. This would help the NIH Director set priorities in his annual budget requests, and help legislators assess whether those requests reflect an adequate allocation of research dollars to the needs of patients in pain.

Third, extra-mural participation is critical to identifying the most pressing research needs in the pain field. Currently, perhaps because pain has no single home at NIH, there is no structured opportunity for either basic scientists or clinicians in the pain field to work with NIH leadership to establish a broad pain research agenda. With the Decade of Pain Control and Research half over, now would seem an opportune time to bring people together to take stock of what has been accomplished, and what remains to be done.

Fourth, NIH needs to invest in infrastructure development in the pain field. Other significant disease categories have either intra-mural or extra-mural centers of clinical and research excellence, and in many cases both, that advance research over years and sometimes decades. This capacity is seriously lacking in pain research.

These are modest suggestions. They will not produce dramatic research breakthroughs, nor bring immediate relief to the millions of chronic pain patients in this country. But they also won't bust any budgets in a time of fierce competition for research dollars. Nor will they complicate the NIH organizational chart at a time when many of you seek to simplify it. I commend them to your consideration, and would be pleased to explore them in more detail with you.

In closing, Mr. Chairman, I want to share a personal perspective. Our center in Ann Arbor is a national referral center for patients with intractable and severe pain problems. Many of those sent to us are children, and most patients are in their working years. The majority come to our center on large dosages of narcotic medications, and despite these, the pain has worsened, and so has the desperation and side effects. Most cannot work or go to school or even care for their families. Despite the challenges, we are able to help many of these people, but many are not helpable. Lives become hopeless.

Mr. Chairman, thank you again for bringing these issues forward to this Committee and in the House. My colleagues and I in the Pain Care Coalition look forward to working with you, Congressman Rogers, and others. Working together, I know we can make a difference for millions who suffer in pain today and every day of their lives.